Community Based Perinatal Palliative Care

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Learning Outcome

After completing this activity, the learner will increase their understanding to describe a model of a community-based perinatal palliative care program applicable in all situations.

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Perinatal Palliative Care: Definition

- Perinatal palliative care is a comprehensive approach to caring for fetuses or neonates with life-limiting illnesses in the perinatal period (from 22 weeks of gestation to 28 days after birth).
- It aims to provide relief from pain and control symptoms while improving the quality of care and well-being of the infants, their families, and healthcare providers.
- This care is holistic and family-centered, addressing not only the physical aspects but also the psychological, social, and spiritual dimensions.
- It involves a multidisciplinary palliative team that may include obstetricians, midwives, geneticists, NICU teams, chaplains, and social workers (psychosocial specialists)

(Dombrecht, L, et al., 2023; Ratislavová, K., et al, 2019)

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Perinatal Palliative Care: Population

The majority of pregnancies complicated by a potentially life-limiting fetal diagnosis, are the result of congenital malformations or chromosomal anomalies :

- •Genetic/Metabolic : (Trisomy 13, Trisomy 18, Osteogenesis imperfect (severe phenotypes), Triploidy, CPT2 deficiency)
- •Cardiac :(Acardia, Inoperable lesions or poor prognosis; complex cardiac defects single ventricle physiology)
- •Neurological Disorders :(Anencephaly, holoprosencephaly ,Pontocerebellar hypoplasia ,Giant encephaloceles and Spinal muscular atrophy)
- •Pulmonary disorders :(Severe pulmonary hypoplasia, Bilateral renal agenesis with hydramnios(Potter's sequence), severe skeletal dysplasias, severe Congenital diaphragmatic hernia, and Severe hydrops fetalis
- •Other: (Large abdominal wall defects, multiple organ anomalies, conjoined twins, premature delivery 23-24 weeks)

(Cortezzo, D. et al., 2020; Vandermeer, R. et al., 2022)

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Role of the Perinatal Program

- With advances in prenatal care and diagnostic technologies, we can now identify life-limiting fetal diagnoses earlier than ever before.
- Families and healthcare professionals often need support in making crucial decisions throughout the pregnancy, delivery, and care of medically complex newborns.
- Our perinatal palliative care consultation, as part of family-centered fetal care, offers opportunities to discuss goals of care and plan for value-driven medical care during the perinatal and postnatal period.
- We are dedicated to exploring various pathways based on families' value systems and helping to formulate a birth plan to guide advance care planning.
- Additionally, we provide compassionate support for memory making and offer bereavement counseling.

(Maher-Griffiths C. ,2022)

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Perinatal Advance Care Planning / Consult

- It is important to comprehend the family value system behind parental decision-making.
- Building rapport and guiding discussions about care goals are critical roles in creating a comprehensive palliative care plan.
- This process usually involves multiple visits and includes the following key points:
  - Exploring the medical understanding of the situation
  - Discussing the meaning of the diagnosis and the balance between hope and reality
  - Identifying the family's worries and concerns
  - Mapping out the family's values system
  - Discussing faith and spirituality
  - Understanding what is most important for the care team to know when caring for the child
  - Validating emotions and seeking clarification
- Additionally, it is essential to devise a birth plan with the family.

- (Cortezzo, D. et al., 2020; Maher-Griffiths C. ,2022)

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Perinatal Birth Plan

- The birth plan should contain a personalized proposal for delivery and neonatal care, prioritizing perinatal palliative comfort care over life-prolonging measures.
- The birth plan must encompass comprehensive assessments and care for the newborn, including crucial aspects such as newborn bonding, skin-to-skin contact, temperature regulation, hydration, feeding, respiratory distress management, and pain control.
- The plan reflects specific patient wishes and be confidently discussed with healthcare providers before delivery including spiritual and emotional support during and after delivery.
- Additionally, it should be meticulously documented in the medical record and readily available for review by the care team.
- It is imperative to emphasize the provisional nature of the plan for neonatal care, and its potential need for reassessment based on postnatal evaluation
- Collaboration with inpatient palliative care team, NICU team, Ethics, and Community Hospice team
- Transition to home in Palliative Care Program or Hospice Program

(American College of Obstetricians and Gynecologists, 2019;Cortezzo, D. et al., 2020; Maher-Griffiths C. ,2022)

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Comfort Care Medications

Medication	Class	Focused Symptom
Morphine	Opioid	Acute Moderate-Severe Pain; Dyspnea
Hydromorphone	Opioid	Acute Pain Moderate – Sever Pain (renal dysfunction); Dyspnea
Fentanyl	Opioid	Acute Moderate-Severe Pain; Dyspnea
Ketamine	blockade of NMDA and HCN1 receptors, dissociative anesthetic	Pain and agitation
Methadone	Long acting Opioid	Chronic Pain
Dexmedetomidine	Alpha2 agonist	Agitation, pain
Gabapentin	Anticonvulsant	Neuropathic pain, neuro-irritability
Acetaminophen	Cox2 inhibitor	Mild pain and fever

Adapted from Cortezzo & Meyer, 2020

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Comfort Care Medications Cont'd

Medication	Class	Focused Symptom
Midazolam	Benzodiazepines	Agitation and dyspnea
Diazepam	Benzodiazepines	Agitation
Lorazepam	Benzodiazepines	Agitation and dyspnea
Ophthalmic atropine drop	Anticholinergic	Secretions end of life
Glycopyrrolate	Anticholinergic	Secretions

Adapted from Cortezzo& Meyer, 2020

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Ethical Considerations

- Perinatal palliative comfort care is among the options available for pregnant patients dealing with pregnancies complicated by life-limiting fetal conditions.
- These options range from pregnancy termination (abortion) to full neonatal resuscitation and treatment
- Providing perinatal palliative care to pregnant patients should be viewed as an opportunity to enhance their autonomy and ensure beneficent care
- Guard against coercion and undue influence from family members, spouses, partners, or even health care providers themselves

(American College of Obstetricians and Gynecologists, 2019)

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Barriers to Perinatal Palliative Care

- A retrospective cohort study involving over 40 children's hospitals found that although neonates accounted for 41% of all hospital deaths, only 2% of them received palliative care services.
- Factors contributing to low perinatal palliative care use include the availability of programs, patient access issues, and physician education and training barriers.

(Keele L, et al, 2013; Samsel C, & Lechner BE, 2015)

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Who Are We

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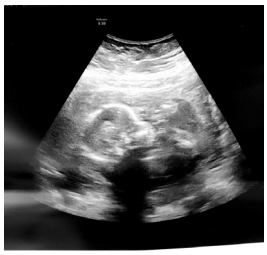
Perinatal Program : Case 1



- RB was a 35-year-old female who joined our perinatal program after being referred by Genetics at 20 weeks of pregnancy
- She received a fetal diagnosis of agenesis of the kidneys and was part of a married couple with a four-year-old sibling who had a congenital hand malformation.
- Additionally, her husband had a history of depression, and her mother was in school to become a Mental Health APRN.
- The Perinatal program communicated with OB, Labor and delivery team
- Childlife and Psychosocial specialist worked with parents and sibling
- Birth plan was developed wit comfort focus and family members present
- No spiritual affiliations
- RB had an uncomplicated spontaneous vaginal delivery at 36 weeks, and the perinatal team was present to provide support during the delivery.
- "Lay Me Down to Sleep" performed the photographs.
- She passed peacefully 8 hours after birth with her family

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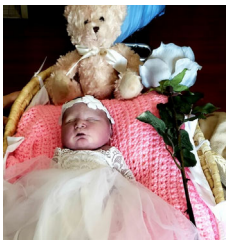

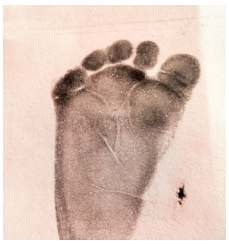

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Perinatal Case 2: Withdraw of Care at Home

- Baby girl S. was initially admitted to the Perinatal Program with a diagnosis of Trisomy 12.
- She spent 5 months in the NICU after being born at 34 weeks gestation. She has a complex medical history that includes mosaic Trisomy 12, tracheomalacia, chronic lung disease, tracheostomy, gastrostomy tube, and is dependent on a ventilator.
- In the past few months, she has experienced worsening pulmonary hypertension and congestive heart failure.
- This led to the administration of multiple medications including digoxin, diuretics, nitric oxide, Sildenafil, Bosentan, and Flolan infusion.
- Baby S. has been dealing with intermittent pulmonary hypertensive episodes, which required sedation, continuous infusions, breakthrough pain medications, and paralytics. - Several specialists were involved in the management of Baby S.'s medical needs to optimize her condition.
- Despite the best medical and surgical management, Baby S. still struggled to maintain adequate oxygenation without being paralyzed and sedated

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Case 2 Continued

- The Inpatient Palliative Care team was consulted and is providing support to both the family and the NICU team.
- The family consists of a mother, father, and three younger siblings, aged 3, 5, and 9.
- Covid-19 restrictions have affected sibling visits and overall family support. - In line with the family's wishes, the Palliative Care team presented potential options.
- The parents have expressed a strong desire for Baby S. to meet her siblings and to pass away at home in a nursery prepared for her.
- There are spiritual concerns as the child has not been baptized, and despite the visitation policy, the parents are insistent on having a ceremony.
- Outpatient Hospice has discussed with the family the possibility of withdrawing care at home and has explained the process to them

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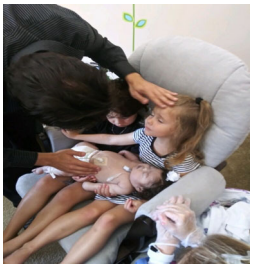

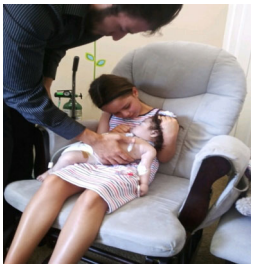

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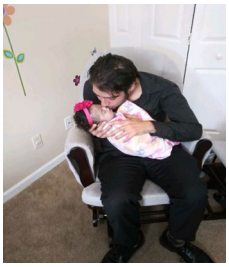

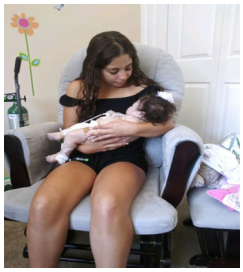

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Memory Making

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Conclusion

- Our perinatal palliative care involves a coordinated approach that includes OB/GYNs, labor and delivery staff, NICU team, inpatient palliative care team, and, if necessary, ethics consultants.
- We encourage options for obstetric and newborn care that prioritize maximizing the quality of life and comfort for newborns with conditions that are considered to be life-limiting in early infancy.
- Our program does not replace prenatal consultations with neonatology, but we are available to provide support.
- We assist in developing a birth plan and provide access to the entire OB, labor delivery, and NICU team. - We offer support and care during the prenatal, birth, and postnatal periods, including bereavement counseling.
- When a life-limiting condition is suspected during pregnancy, it is essential to provide pregnant patients with comprehensive information to enable them to make an informed and voluntary choice regarding their care

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